

# **Mortality**

# **ANNUAL REPORT**

**FY 2012**

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This is the eleventh of a series of annual reports on mortality, mortality trends and related information pertaining to the health and quality of care received by individuals served by the Connecticut State Department of Developmental Services. Reports focus on an analysis of mortality data and specific findings resulting from the Connecticut DDS mortality case review process. Reports are scheduled for publication March of each year.

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*Issue Date: March, 2013*

# Mortality ANNUAL REPORT – 2012

Issue Date: March 2013

## CT DDS Mortality Report

### SECTION ONE OF THIS REPORT:

#### *CT DDS MORTALITY REVIEW PROCESS*

This section describes the CT DDS Mortality Reporting and Review Process.

### SECTION TWO OF THIS REPORT:

#### *ANALYSIS OF ALL CT DDS MORTALITIES*

This section includes information and data concerning all deaths of individuals served by DDS who were listed in the CT DDS data base and died during the 2012 fiscal year (July 1, 2011- June 30, 2012) including death rates and life expectancy.

### SECTION THREE OF THIS REPORT:

#### *DATA GENERATED BY THE CT DDS MORTALITY REVIEW PROCESS*

This section includes information and analysis of data generated for the 146 deaths reviewed by the DDS nurse investigators, regional review committees and Independent Mortality Review Board (IMRB) for the period of July 1, 2011 – June 30, 2012.

### SECTION FOUR OF THIS REPORT:

#### *MORTALITY TRENDS CT DDS*

This section provides an analysis and synthesis of CT DDS mortality data over time.

### SECTION FIVE OF THIS REPORT:

#### *LEADING CAUSES OF DEATH*

This section presents CT DDS leading cause of death data.

### SECTION SIX OF THIS REPORT:

#### *BENCHMARKS*

This section presents and compares CT DDS, National, and State mortality statistics and leading cause of death information.

### SECTION SEVEN OF THIS REPORT:

#### *SUMMARY MORTALITY CASE REVIEW FINDINGS*

This section includes information on the findings identified through the DDS mortality review process and examples of quality initiatives implemented as a result of the CT Mortality Review Process.

**Appendix:** Includes demographic information on the population served by the CT DDS

This report represents a review of the period between July 1, 2011 to June 30, 2012.  
Data in this report was obtained from the CT DDS Database system.

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## Executive Summary 2012 Report

- There were 211 deaths resulting in a crude mortality rate of 13.13/1000
- The strongest predictors of mortality were age, mobility status and the need for special assistance when eating
- The average age of death for individuals with ID was 60.8 years
- Starting early in the fifth decade of life there was a progressive increase in the mortality rate for people with intellectual disabilities
- People with intellectual disabilities have a decreased life span as compared to the general population which may be related to the onset of multiple chronic and acute co-morbidities at a younger age
- Mortality is related to the level of intellectual disability, the greater the level of disability the higher the mortality rate
- Heart disease continues to be the leading cause of death in the CT DDS population (21.8%)
- Aspiration pneumonia/pneumonia accounted for 17.1% of all deaths
- The incidence of deaths related to cancer in the DDS population (13.3%) was lower than the national (22.9%) and state (23.7%)<sup>25,26</sup>
- Accidental deaths continue to occur at a rate below that of the general state and national population<sup>25, 26</sup>
- The average age of death for people with Down syndrome was 55.5 years
- Cardiac Arrest was the leading cause of death for people with Down syndrome
- Hospice supports were provided in 38% of the reviewed deaths which allowed individuals to remain in their home residences in the final stages of a terminal illness

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## CT DDS MORTALITY REVIEW

An important component of the quality and risk management systems present within DDS involves the analysis and review of deaths to identify important patterns and trends that may help increase knowledge about risk factors and provide information to guide systems enhancements. Consequently CT DDS continues to embrace a planned organization wide approach to design performance measurement, analysis and improvement by collecting information pertaining to the deaths of all individuals served by the department. The CT DDS mortality review system has proven to be a valuable quality assurance mechanism providing information to trigger corrective action and reduce future risk.

The CT DDS mortality review process provides a retrospective analysis

### THAT

- assures compliance with standards
- reduces adverse events
- leads to ongoing improvement

### AND GENERATES

- changes in policy and procedure
- protocol development
- practice standards
- focused training
- systems improvement strategies

## CT DDS DEATH REPORTING PROCESS

Per State of Connecticut Executive Order No. 42, the Department of Developmental Services shall report all deaths of persons placed or treated under the direction of the Commissioner of the Department of Developmental Services to the Office of Protection and Advocacy whether or not abuse or neglect is suspected or contributed to the individual's death.

The CT DDS death reporting process is a dynamic process that ensures that all deaths are immediately reported to the department and death report forms are submitted to the department within 24 hours of the death notification.

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## **SECTION ONE: CT DDS MORTALITY REVIEW PROCESS**

### **CRITICAL COMPONENTS OF THE CT DDS MORTALITY PROCESS:**

- Uniform death reporting system
- Screen individual death reports with standard information
- Standardized mortality review process (regional and state)
- Medical professionals participate in the process
- External stakeholders included in the review process
- State level interdisciplinary/independent mortality review board (IMRB) aggregates mortality data over time to identify trends
- Direct link between mortality findings and improvement
- Publically report and document mortality information (Annual CT DDS Mortality Report)

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Section One Continued

Connecticut law (which comprises statutes and executive order) currently requires CT DDS to review the death of anyone for whom it has direct or oversight responsibility for medical care. The review must cover the events, overall care, quality of life issues, and medical care preceding the death to assure that a vigorous and objective evaluation and review of the circumstances surrounding untimely deaths takes place. The CT DDS does not review the deaths of individuals who lived at home with their families or who were placed by their family/guardian into a licensed nursing facility.

CT DDS has established a three tier mortality review process as part of its quality assurance system to trigger corrective action and reduce future risk for people. As noted below, the three tier system includes an Abridged Review, Regional Mortality Review Committee and Independent Mortality Review Board. In addition, the mortality process includes a Medical Desk Review by trained Nurse Investigators and a final review of all IMRB cases by the CT DDS Commissioner and Director of Health and Clinical Services (IMRB Chair).

## The mortality review process seeks to address the following questions:

- Was the death anticipated or unexpected?
- Could this death have been prevented?
- Are there systems issues identified in the course of the review?
- Are there case specific issues identified in the course of the review?
- What actions should DDS take to improve the health and safety of consumers?

### Abridged Review Criteria for Review

Any death that had a DNR in force that was reviewed per the DDS DNR review process, was related to a pre-existing condition/diagnosis, did not have an allegation/investigation of abuse/neglect at time of death and did not have a post mortem examination. Individual was not a Class Member and did not reside in a ICF/MR.

### Regional Mortality Review Committee Criteria for Review

Any death where the department bears direct or oversight responsibility for medical care.

### Independent Mortality Review Board Criteria for Review

- Determined necessary by the regional mortality review committee
- Medical, health or residential care concerns
- Post mortem examination
- Suspicion of abuse/neglect, etc.
- Ongoing abuse/neglect investigation

Assume immediate jurisdiction and conduct an expedited review when determined necessary by the Commissioner or the OPA Executive Director if it is likely that the death occurred because of abuse or neglect or at the request of the Director of Quality Management Services and/or the Director of Health and Clinical Services.

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Section One Continued

## Nurse Investigators Medical Desk Review

In addition to the regional mortality review committees and the Independent Mortality Review Board, the DDS death reporting and mortality review process requires that all deaths are reported to a **Nurse Investigator (NI)** who is assigned to the DDS Investigations Division. The Nurse Investigator conducts a **Medical Desk Review (MDR)**, an abbreviated mortality review to determine the need for an abridged review, a comprehensive review by a regional mortality committee and/or the Independent Mortality Review Board or if an immediate investigation of the death by another state agency is warranted.

## Role of the Nurse Investigators

The Nurse Investigator will forward the Medical Desk Review and associated documents to the DDS Director of Investigations, DDS Director of Health Services (Chair of the Regional Mortality Review Committee) and the DDS Director of Health and Clinical Services (Chair of the Independent Mortality Review Board) when:

- Abuse or neglect is suspected according to DDS abuse/neglect policies and procedures
- Systems deficiencies are identified or suspected
- For routine mortality review as defined in DDS procedure

## Independent Mortality Review Board Membership

Members of the Independent Mortality Review Board (IMRB) are appointed by the CT DDS Commissioner and Executive Director of the CT Office of Protection and Advocacy for DD and include:

- DDS Director of Health and Clinical Services (Chair)
- DDS Director Division of Investigations
- DDS Director Division of Quality Management
- Associate Medical Examiner  
(State Office of the Chief Medical Examiner)
- Community based physician
- State Office of Protection and Advocacy
- State Department of Public Health
- Executive Director private provider agency
- Family representative

## Regional Mortality Committee Membership

Members of the Regional Mortality Review Committees are appointed by the regional or training school (STS) Director and include:

- DDS Regional Health Services Director (Chair)
- Medical Director (for STS campus)
- Non DDS registered nurse
- Non DDS consumer advocate
- DDS Residential Manager
- DDS Assistant Regional Director
- DDS abuse/neglect liaison
- Family representative

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## SECTION TWO: ANALYSIS OF ALL CT DDS MORTALITIES (JULY 1, 2011 – JUNE 30, 2012) NUMBER OF DEATHS REPORTED = 211

### Overall Mortality Rate

During the 12 month time period between July 1, 2011 and June 30, 2012 a **total of 211** individuals supported by CT DDS passed away **resulting in a mortality rate of 13.13** (Figure 1 & 2 below). Both the number of deaths and mortality rate increased in FY 12.

Figure 1

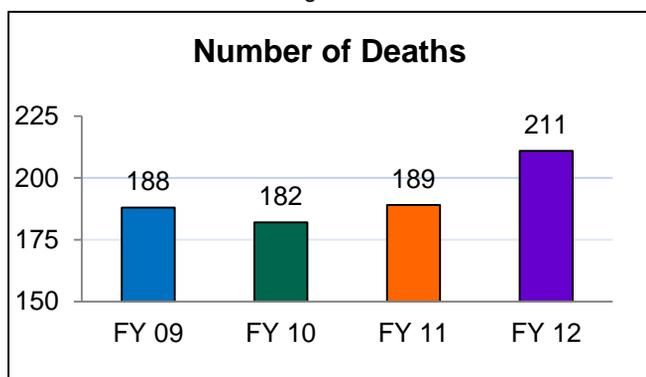
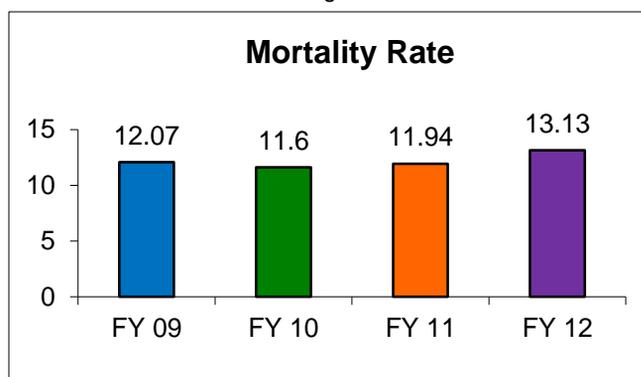


Figure 2



### Mortality and Residence

As can be seen in Figure 3 (to the right), forty-six percent of deaths occurred in settings that were not operated, funded or licensed by CT DDS.

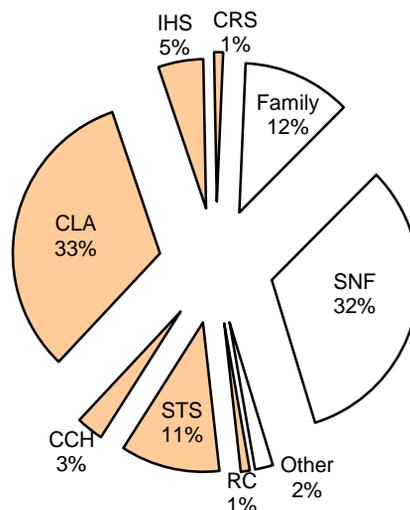
	% Deaths	% DDS population
CLA	33	24
SNF	32	2
Family	12	57
STS	11	2
CCH	3	3
IHS	5	5
Other	2	3
CRS	1	3
RC	1	1

SNF = skilled nursing facility; RC = regional center; STS = Southbury Training School; CLA = community living arrangement (group home); CCH = community companion home (formerly called CTH); IHS = individualized home supports; CRS = continuous residential supports, Family = live with family at home or independently.

**Shaded areas represent settings operated, funded or licensed by CT DDS.**

Figure 3

### Residence at Time of Death



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Figure 4

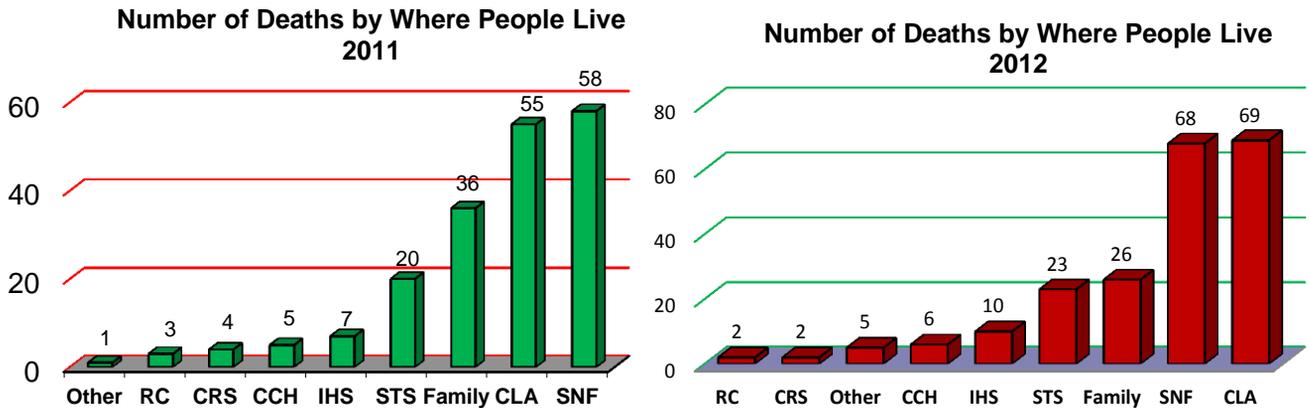


Figure 4 (above) depicts the actual number of deaths by where people live. This year the greatest number of deaths occurred in CLAs followed by skilled nursing facilities, family homes and STS. Of note: Sixty-two (62%) of the people DDS supports live in family homes or in their own home with individualized supports, 24% in group homes (CLA's) and only 2% in skilled nursing facilities.

Figure 5

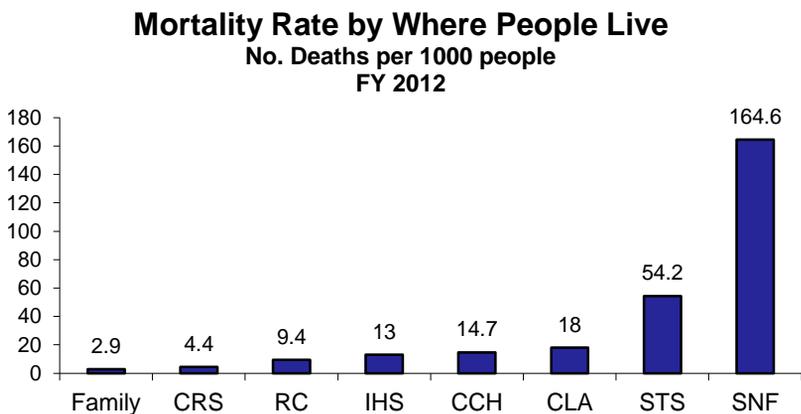


Figure 5 (left) depicts the number of people who died for every 1000 people served by type of support.

Of note: In general, individuals supported by DDS who live in skilled nursing facilities and at STS tend to be older. In addition, residents of skilled nursing facilities have considerable health comorbidities.

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Section Two Continued

## Mortality and Residence

**Family Home:** People who live with their family without significant residential DDS supports or independently represent 57% of the DDS population. However, in FY 2012 only 26 deaths (12.3% of all deaths) occurred in a family home with an associated mortality rate of 2.9. All CT DDS deaths of children were for those who lived with their families. Thirteen of the 26 people died in a hospital, hospital emergency department or hospice.

**CLA:** These settings serve people with varying levels of intellectual disabilities who require 24 hour supervision for their health and direct care supports. In FY 2012, 69 or 32.7% of all deaths occurred in CLA's compared to 29.1% in FY 11. Forty-eight of the 69 people died in a hospital, hospital emergency department or SNF.

**CCH:** There were 6 reported deaths in the community companion homes compared with 5 reported deaths in FY 2011. The CCH mortality rate of 14.7 was greater than the mortality rate for people living at home with their family or people living in their own home or independently with supports. People living in CCH's represent 2.5% of the DDS population and accounted for 2.8% of the reported deaths. Five of the 6 people died in a hospital or hospital emergency department.

**CRS:** People receiving 24 hour supports in their own homes, People receiving continuous residential supports in their own homes, in most cases, are less medically involved than people living in other settings. Only 0.9% of reported deaths occurred in this environment. One of the 2 people died in a hospital.

**IHS:** Similar to people living in CRS, however, this population does not require 24 hour support. As with CRS, people receiving individualized home supports in their own homes, in most cases, are less medically involved than people living in other settings. This year 4.7% of reported deaths occurred in this environment compared with 3.7% last year. Three of the 10 people died at their home the rest (7) died in the hospital, hospital emergency department or SNF.

**STS:** The higher mortality rate of 54.2 is not surprising as this larger campus setting serves a population of older adults (average age of 63.3 years). Twenty-three deaths were reported at STS this past fiscal year representing 10.9% of all DDS deaths. Last year the Training School accounted for 10.6% of all deaths. Nine of the 23 people died in a hospital or hospital emergency department.

**RC:** Less than 2% of DDS consumers reside at DDS regional centers. Only 2 RC residents died in FY 2012 accounting for 0.9% of all DDS deaths. Both of these individuals were pronounced at the regional center.

**SNF:** Only 2% of people served by CT DDS live in a skilled nursing facility. This older (average age 65.5 years) and medically fragile population accounted for 68 or 32.2% of all reported deaths. People living in licensed nursing facilities had the highest mortality rate 164.6 per thousand. Fifteen percent (15%) of all DDS consumers over 65 years of age live in a skilled nursing facility. It is important to note that 22 of the 68 people died in a hospital, hospital emergency room or hospice.

- Community Living arrangement (CLA): 24 hour support is provided with staff in small group home settings. People share an apartment or house also known as a group home.
- Community Companion Home (CCH): A family setting that is not the consumer's own family. CCH provider has received training and is licensed by DDS to provide services. (Formerly known as CTH, Community Training Home.)
- Continuous Residential Supports (CRS): 24 hours of support for consumers to live in their own home.
- Individualized Home Supports (IHS): Less than 24 hours of support for consumers to live in their own home. Staff support may be from a few hours a day to only a few hours a month depending on the support needs of the individual.
- Southbury Training School (STS): 24 hour support is provided in a large campus setting serving a population of older adults.
- Regional Center (RC): Regional Centers are facilities for over 16 people that provide 24 hour staffing.
- Skilled Nursing Facility (SNF): A Department of Public Health licensed nursing facility for people requiring skilled nursing level of care not licensed or funded by the Department of Developmental Services also known as a nursing home.

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## Mortality and Gender

Table 1

Mortality Rate by Gender - 2012

GENDER	All Individuals Served by DDS	Total Number of Consumers	No. Deaths	Percentage of Deaths	Rate (No. Deaths Per 1000)
Men	58%	9,135	107	51%	11.57
Women	42%	6,723	104	49%	15.23
<b>Total</b>	<b>100%</b>	<b>15,858</b>	<b>211</b>	<b>100%</b>	<b>13.13</b>

In FY 2012 both the number of males and females who died within the DDS was similar to the gender distribution of those people served by the department.

Figure 6

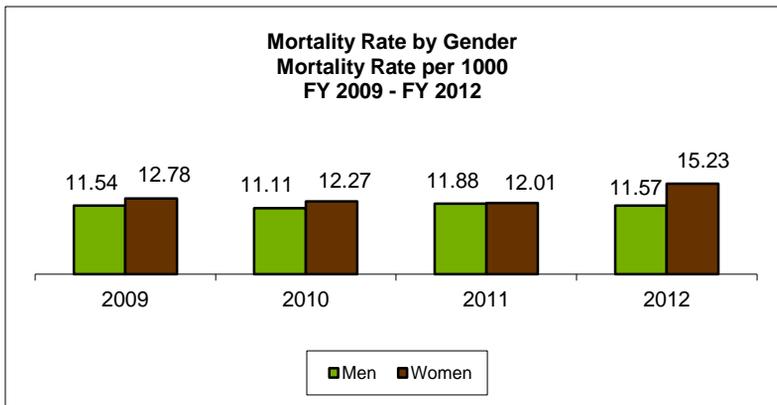
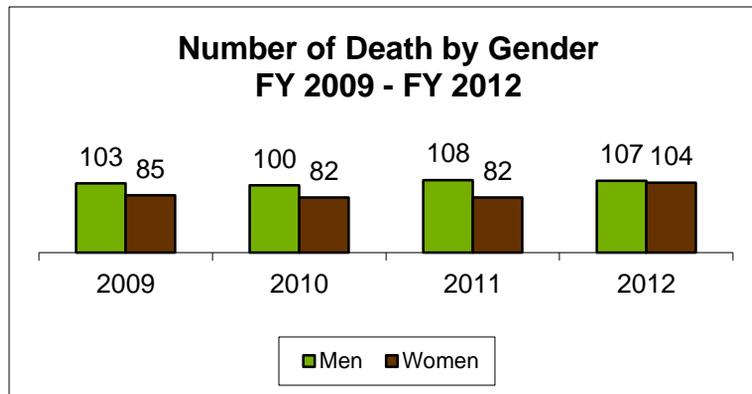


Figure 7

Although there are year to year variations in the actual number of deaths by gender, the data consistently demonstrate that more men than women die each year and that women have a higher mortality rate.

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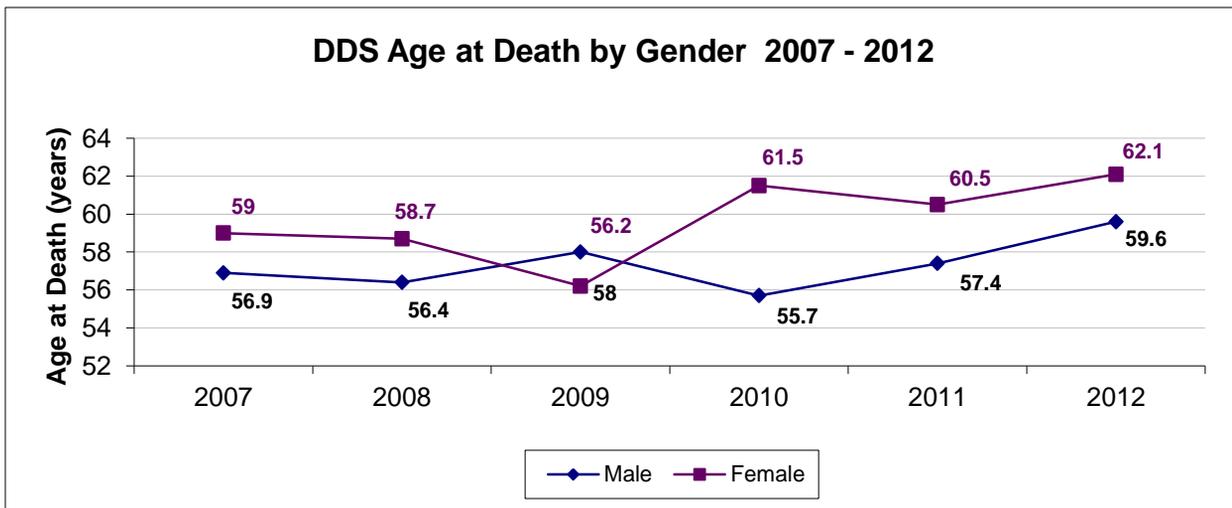
## Mortality and Age

Table 2

### Age of Death

Year	Men	Women	Average Age
CT DDS FY 2012	59.6	62.1	60.8
CT DDS FY 2011	57.4	60.5	58.7
CT DDS FY 2010	55.7	61.5	58.3
CT DDS FY 2009	58	56.2	57.1

Figure 8

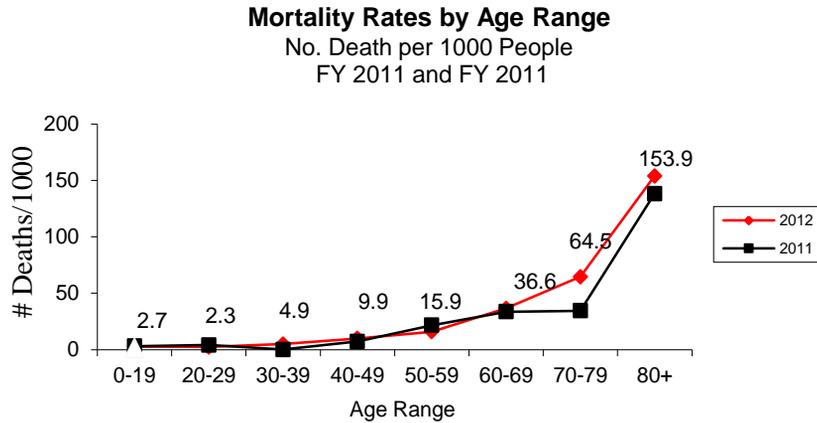


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Figure 9



The relationship between **age** and **mortality** demonstrates the expected trend, with the mortality rate increasing as people served by DDS get older. As seen in Figure 9, there is an increase in the mortality rate that begins early in the fifth decade of life that continues to increase with advancing age. This finding is consistent with previous CT DDS mortality rate by age data.

Table 3

## Mortality Age Range Distribution Data FY 2012

AGE RANGE	# OF DEATHS	% OF DEATHS	MORTALITY RATE
Age 0-19	9	4.3%	2.7
Age 20-29	8	3.8%	2.3
Age 30-39	11	5.2%	4.9
Age 40-49	24	11.4%	9.9
Age 50-59	38	18%	15.9
Age 60-69	52	24.6%	36.6
Age 70-79	35	17%	64.5
Age 80+	34	16.1%	153.9
<b>TOTAL</b>	<b>211</b>	<b>100%</b>	

Mortality statistics for the DDS population in Table 3 reveal a progressive increase in the mortality rate as the age range increases.

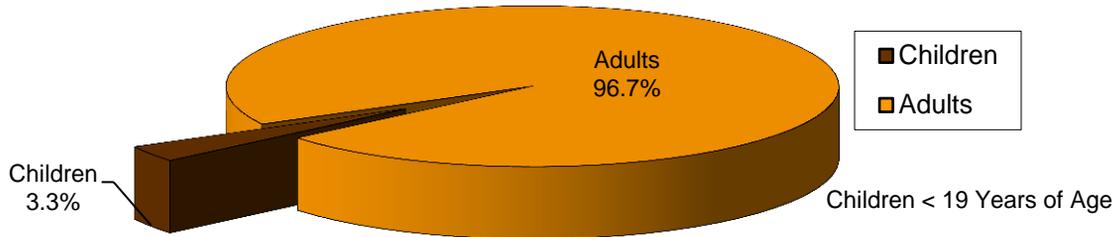
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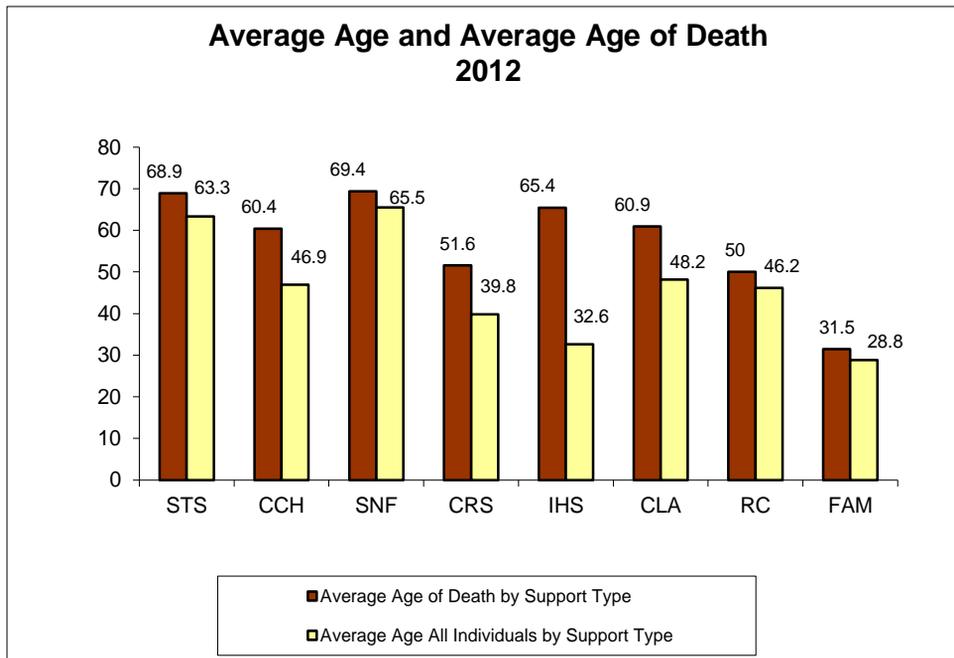
Figure 10

## Deaths of Children and Adults



In FY12 seven children died and they all lived at home with their family.

Figure 11



The average age of death in the CT DDS population is 60.8. Almost all of the children served by DDS live at home with their family that translates into a much lower average age and age of death. Excluding children the average age of death in the CT DDS population is 62.5 years.

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## SECTION THREE: DATA GENERATED BY THE CT DDS MORTALITY REVIEW PROCESS

### IMPORTANT PLEASE NOTE:

THE INFORMATION PRESENTED IN THIS SECTION SUMMARIZES ONLY THOSE DEATHS THAT WERE REVIEWED BY THE NURSE INVESTIGATORS, REGIONAL COMMITTEE AND/OR STATE INDEPENDENT MORTALITY REVIEW BOARD IN FY 2012 THEREFORE, THE MORTALITY DATA WILL DIFFER FROM THE INFORMATION PRESENTED AND DISCUSSED IN SECTION TWO OF THIS REPORT

DDS NURSE INVESTIGATORS/MORTALITY COMMITTEE/BOARD REVIEWS = 146 cases (of total 211 deaths)

\*\* 40 of the 146 cases reviewed were Abridged Reviews \*\*

### Community Hospice Support

The concept of end of life planning including hospice care has been embraced by the CT DDS and is routinely requested and provided for individuals served by DDS who live in all settings, including regional centers, Southbury Training School, community living arrangements, community companion homes, continuous residential supports, individualized home supports and family homes. This includes state of the art palliative and hospice care to provide end of life support, hope and comfort to individuals either in the home or in a hospital setting.

The use of hospice services allowed CT DDS to support people through the final stages of a terminal illness while remaining in their current residence. Forty individuals received hospice services: 35% lived at the training school, 33% lived in a nursing home, 25% lived in a community living arrangement, 5% lived in a community companion home and 3% lived in a continuous residential support. The average age of death for people receiving hospice services was 65.9.

Forty people (38% of all reviewed deaths) received hospice supports \*

### Autopsies/Post Mortem Examinations

Autopsies are performed by the Office of the Chief Medical Examiner (OCME) for those deaths in which the OCME assumes jurisdiction or by hospital based pathology departments when DDS requests and the family consents to the autopsy.

#### GUIDELINES FOR REQUESTING AUTOPSIES

- certain sudden or unexpected deaths in which the cause of death is not due to a previously diagnosed condition or disease
  - deaths involving an earlier accident or trauma
  - deaths involving questionable contributing factors
  - cases involving an allegation of abuse or neglect

Number of post mortem examinations performed: 13 (9% of reviewed deaths)

Number of post mortem examination performed by CT OCME: 5

\* Does not include Abridged Reviews

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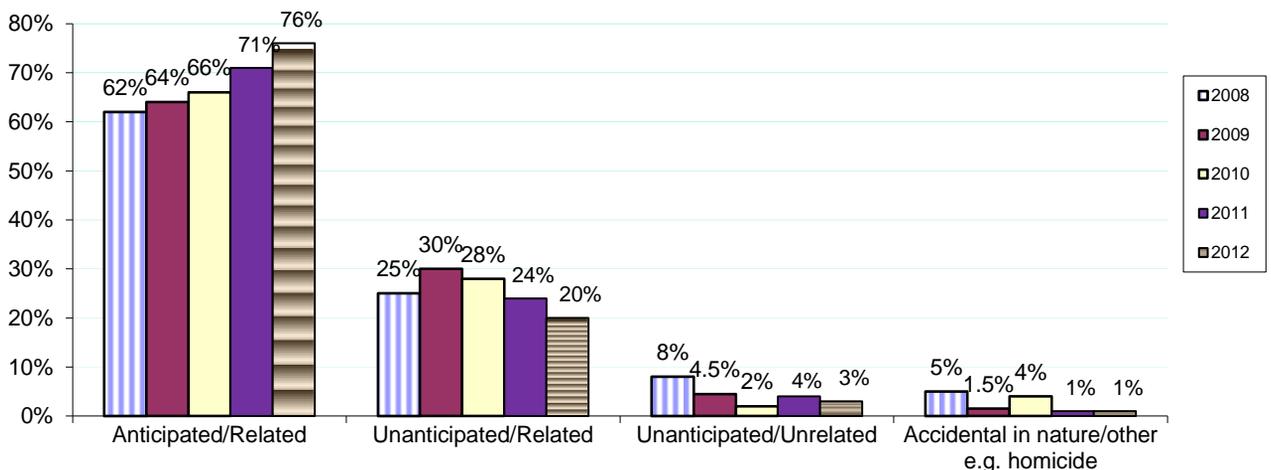
## Predictability

Analysis of the mortality review data indicates a relationship between an individual's pre-existing diagnosed medical condition(s) and his/her immediate cause of death (see Figure 12 below). In ninety-seven percent of all deaths, an individual's immediate cause of death was related to a known or previously diagnosed medical condition/disease. For example: An individual who died as a result of a cardiac arrest had a medical history that included coronary artery disease.

- Death was anticipated and related to a preexisting diagnosis: 76%
- Death was unanticipated but related to a preexisting diagnosis: 20%
- Death was unanticipated and unrelated to a preexisting diagnosis: 3% (includes accidental deaths)

Figure 12

### Predictability of Death 2008 - 2012



#### OF NOTE:

The CT DDS data illustrates that for people over the age of 65 the cause of death was directly related to a pre-existing or known medical condition 100% of the time.

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Section Three Continued

## Context: Manner of Death for Cases Reviewed

According to Connecticut State law, the Office of the Chief Medical Examiner (OCME) determines the cause of death and the manner of death: **natural, accident, suicide, homicide** or **undetermined**.

In the State of Connecticut deaths for which the OCME does not assume jurisdiction, pronouncement is made by a private physician. In these cases the manner of death **must** be classified as natural. According to state statute any other manner of death must be determined by the OCME.

Of the 146 cases reviewed during FY 12, 144 (99%) were classified as **due to natural causes**. Two cases were determined to be the result of an accident.

Table 4

### FY 12 Manner of Death

<i>Manner of Death</i>	<i>No.</i>	<i>Percent</i>
<i>Natural</i>	<i>144</i>	<i>99%</i>
<i>Accident</i>	<i>2</i>	<i>1%</i>
<i>Total</i>	<i>146</i>	<i>100%</i>

Cause of death for the deaths determined by the CT OCME to be accidental in nature:

Choking	(1)
Olanzapine Intoxication	(1)

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Section Three Continued

## UNANTICIPATED/UNRELATED DEATHS:

Of the 5 deaths that were unanticipated and not related to a known condition 1 was due to an accident and 4 were due to natural causes. The cause of mortality for the unanticipated deaths due to natural causes was cardiac arrest (2), cardiac arrhythmia (1), urosepsis/nephrolithiasis (1).

## ACCIDENTAL DEATHS

One case of accidental death was the result of choking, the other one was the result of Olanzapine intoxication.

## **DNR**

Per Connecticut State Statute, CT DDS has an established procedure which requires that **specific criteria must be met along with a special review process** for all withholding cardiopulmonary resuscitation (DNR) orders to be issued/implemented for persons who are placed and treated under the direction of the Commissioner of DDS. Documentation regarding end of life planning and withholding of cardiopulmonary resuscitation is required per CT DDS policy.

**Do Not Resuscitate** (DNR) orders are medically indicated when an individual's attending physician and another physician (second opinion) have diagnosed that an individual is in the final stages of a terminal disease or condition, or is permanently unconscious based upon appropriate tests and studies. This confirmation by the attending physicians that an individual has a terminal disease or condition is reviewed by DDS medical staff (Health Services Directors and in some cases Director of Health and Clinical Services).

For the 146 mortality cases reviewed in FY 2012

**109 cases had a DNR order in place**  
**94% of the DNR orders were formally reviewed by DDS**  
**100% of the DNR orders met the established DDS medical criteria**

In 6% of all cases in which a DNR was ordered by a medical practitioner DDS was not notified prior to the implementation of the DNR order as is required by DDS procedure. However, the DDS mortality review process determined that in every case the medical criteria to support the decision to initiate the DNR was met.

OF NOTE: Eighty-eight percent (88%) of DDS consumers residing in *skilled nursing facilities* had a DNR order in place at the time of their death.

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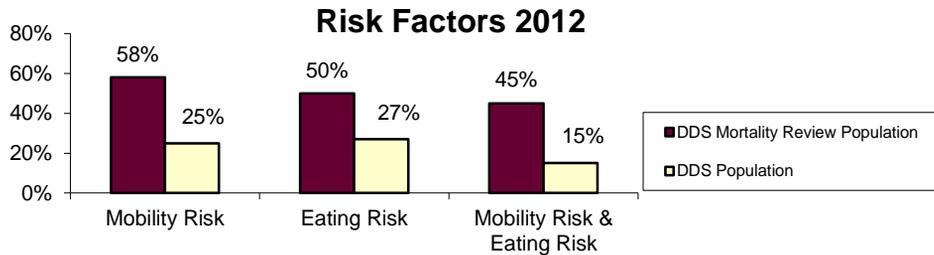
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Section Three Continued

## Risk Factors

Mobility impairments and dysphagia/swallowing risks are well known risk indicators that place individuals at significantly higher risk of morbidity and mortality. CT DDS mortality data has consistently demonstrated that people who require the need for special assistance when eating and those who cannot ambulate without assistance have a greater mortality rate. Therefore the CT DDS mortality review process carefully analyzes the presence or absence of these two risk indicators. Once again the FY 2012 data illustrates the relationship between these risk factors and mortality (see Figure 13 below).

Figure 13



It is well documented in the literature that the more compromised an individual's level of mobility, the greater the likelihood of death.<sup>3,9,10</sup> CT mortality data supports the importance of mobility as an indicator of morbidity and mortality. In FY 2012, sixty-one (58%) of the deceased did not ambulate independently.

<p><b>* MORTALITY REVIEW POPULATION ONLY</b></p> <p>58% did not ambulate independently 50% did not eat independently</p> <p>* Does not include Abridged Reviews</p>	<p><b>* TOTAL DDS POPULATION</b></p> <p>25% do not ambulate independently 27% do not eat independently</p> <p>* Does not include Family Homes</p>
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Of note: Information regarding the presence and/or risk of silent aspiration is not available and therefore is not included in the eating risk factor data.

Level of Intellectual Disability and Mortality Rate

	2010	2011	2012	Percent of Population
<b>Mild</b>	10.1	10.8	<b>9.4</b>	39
<b>Moderate</b>	10.7	6	<b>10.5</b>	28
<b>Severe</b>	21.7	16	<b>11.3</b>	16
<b>Profound</b>	28.8	26.1	<b>25.8</b>	15

Table 5

Table 5 above illustrates the relationship between an individual's level of intellectual disability and mortality rate. There is an inverse relationship between the level of intellectual disability and the mortality rate within the DDS population. Over the years, individuals with severe or profound intellectual disabilities have a higher mortality rate than those with moderate or mild intellectual disability.

Of note: Traditionally intellectual disabilities have been divided into four levels of severity based largely on IQ scores. Although this classification system is no longer used by CT DDS, data is included for longitudinal comparative purposes.

# Mortality ANNUAL Report - 2012

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Section Three Continued

## Investigations

### Office of Protection & Advocacy / Abuse Investigations Division

CT DDS must report all deaths to the Office of Protection and Advocacy for Persons with Disabilities Abuse Investigations Division (OPA/AID) which determines if abuse or neglect was involved in the death.

Of the 146 mortality cases reviewed by DDS, 12 cases were investigated by either the OPA/AID or the DDS through its Investigations Division when abuse or neglect is suspected to have contributed to a person's death. In several cases, deaths that were investigated by the Office of Protection and Advocacy were also referred to and investigated by the CT Department of Public Health.

<u>Disposition of OPA/AID Cases</u>	
<i>Neglect substantiated</i>	<b>2</b>
<i>Neglect not substantiated</i>	<b>2</b>
<i>Cases still open</i>	<b>8</b>

In the cases where neglect was substantiated, the lack of supervision by direct care staff, delay in treatment, delay in recognition of a changing health condition, lack of programmatic safeguards and monitoring of an individual's health care status led to a chain of events that may well have contributed to the individual's death.

### Department of Public Health

The CT Department of Public Health investigates the quality of care/practice by licensed practitioners and licensed healthcare facilities that include hospitals, long term care/nursing facilities, dialysis facilities, ambulatory care centers and outpatient surgical centers.

During FY 2012 five (5) mortality cases were referred by the regional mortality committee or IMRB to the **State of Connecticut Department of Public Health** (DPH) Health Systems Regulation Division for further investigation by the Facilities and/or the Practitioner and Licensing Section.

#### Disposition of DPH Investigations

<u>Practitioner Division Referrals- (0)</u>
cases open - 0
cases closed - 0
citations, violations found - 0

<u>Facility Division Investigations - (5)</u>
cases open - 4
cases closed - 1
citations, violations found - 0

# Mortality ANNUAL Report - 2012

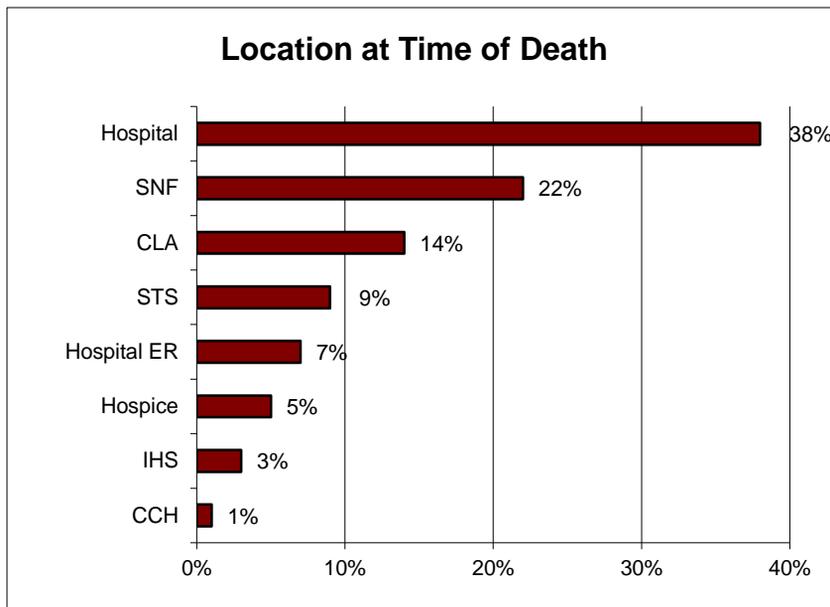
Issue Date: March 2013

Section Three Continued

## Pronouncement of Death (Location at Time of Death)

Figure 14 below depicts the location where death was pronounced.

Figure 14



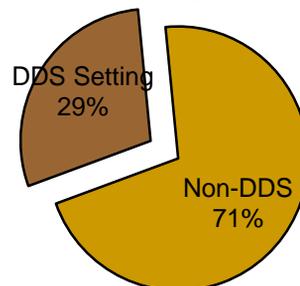
KEY: Location of Death

- Hospital = Admission to the hospital as an inpatient, death occurred in the hospital.
- Hospital ER = Evaluated in hospital ER, died in ER while receiving treatment, not admitted to the hospital.
- All Other = Died where the person lived or worked or other community location.

Figure 15

### Where People Died FY 2012 Mortality Reviews

As can be seen in Figure 15 to the right, 71% of all deaths reviewed by the mortality review committee during FY 12 occurred outside of a DDS operated, licensed or funded residential setting, this represents a decrease in the number of people dying outside of a DDS setting compared to FY 11 (73%).



## ***SUMMARY OF MORTALITY DATA***

***for the 146 deaths that were reviewed in FY12***

- **100%** of required cases were reviewed **Regionally**.
- **25%** of all cases were reviewed by the **IMRB**.
- **38%** of the individuals received **Hospice** supports prior to their deaths. \*
- **9%** of the individuals had **Autopsies** performed.
- **96%** of all deaths were **Related** to an existing medical diagnosis.
- **75%** of the individuals had a **DNR** order in place at the time of death.
- **45%** of the individuals had two **Risk Factors** (non-ambulatory and could not eat without assistance). \*
- **99%** of the deaths reviewed were due to **Natural** causes.
- **2** number of deaths that were classified as **Accidental**.
- **5** number of referrals to **Department of Public Health**.
- **13** number of referrals to **Office of Protection & Advocacy Abuse Investigation Division**.
- **2** number of cases **Neglect** was substantiated by OPA or DDS.

\* Does not include Abridged Reviews

# **Mortality ANNUAL Report - 2012**

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## **SECTION FOUR: MORTALITY TRENDS CT DDS**

**For the past twelve years the Connecticut Department of Developmental Services has collected, reviewed and analyzed mortality data.**

**Data collection has focused on mortality and residence, mortality and age, mortality and gender and leading causes and factors associated with death.**

**The consistency of the cumulative data/statistics from one year to the next seems to validate and support the trends and findings identified within the intellectual disability population group served by the State of Connecticut Department of Developmental Services.**

# Mortality ANNUAL Report - 2012

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Section Four Continued

Figure 16

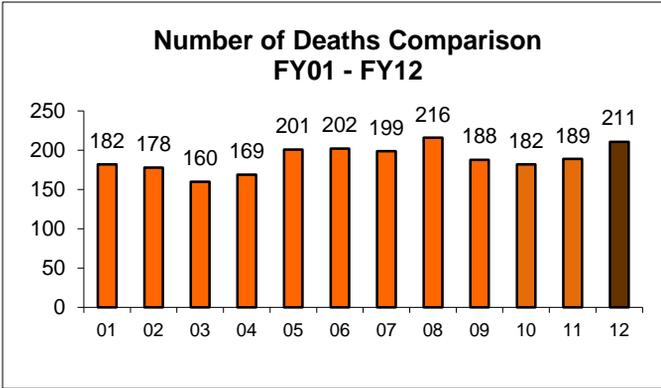
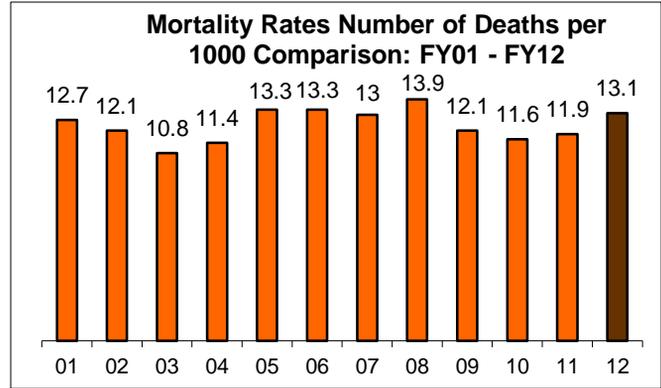


Figure 17



Figures 16 and 17 depict on an annual basis the number of deaths and the average death rate for FY 2001 - 2012 within the population served by DDS. The death rate average over the twelve year period of time is 12.43/1000 people.

Figure 18

Mortality Rate by Where People Live  
7 Year Trend

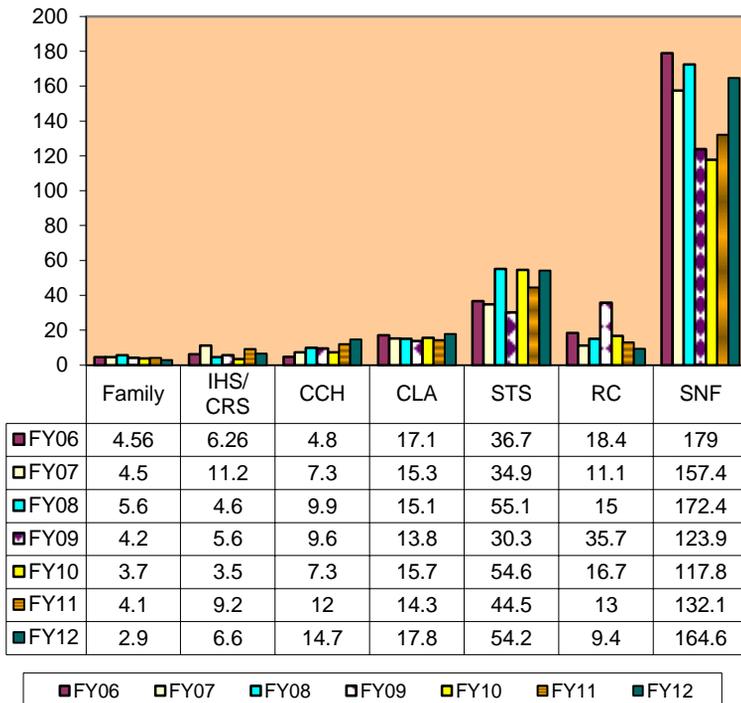


Figure 18 (to the left) compares the death rate (the number of deaths per 1000 persons served) for the past seven (7) fiscal years by type of support.

Historically, individuals residing in residences (SNF, campus) that require more intensive nursing supports and medical oversight due to their compromised health status have a greater death rate than people living in other types of settings. For FY 12 there was a variation in this trend with a decrease in the death rate in the Regional Center.

*Caution must be exercised in reviewing this data since the actual number of deaths in some of these support settings are relatively small.*

# Mortality ANNUAL Report - 2012

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Section Four Continued

Table 6  
Mortality and Gender  
(2003 - 2011)

Year	# Deaths Men	# Deaths Women	Mortality Rate Men	Mortality Rate Women
2003	96	64	11.54	9.84
2004	87	82	10.47	12.57
2005	106	95	12.40	14.38
2006	102	100	11.86	15.11
2007	100	99	11.61	15.13
2008	122	94	13.8	14
2009	103	85	11.54	12.78
2010	100	82	11.11	12.27
2011	108	81	11.88	12.01
<b>2012</b>	<b>107</b>	<b>104</b>	<b>11.57</b>	<b>15.23</b>

Over the past ten years more men died annually than women and with only one exception (2003) the mortality rate for women exceeded the mortality rate for men.

Figure 19

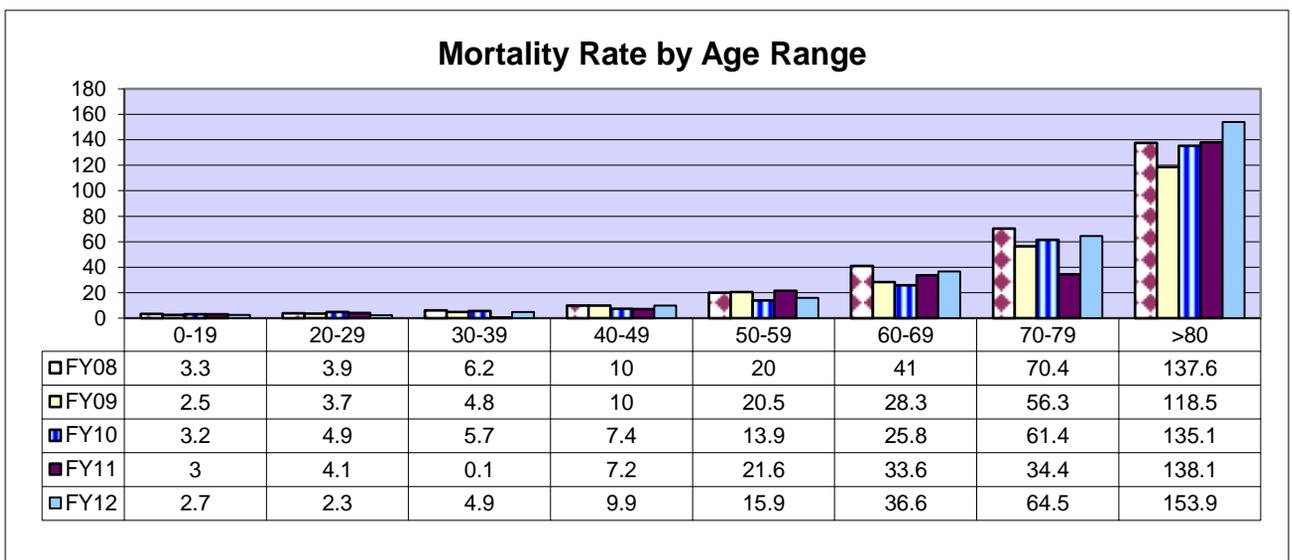


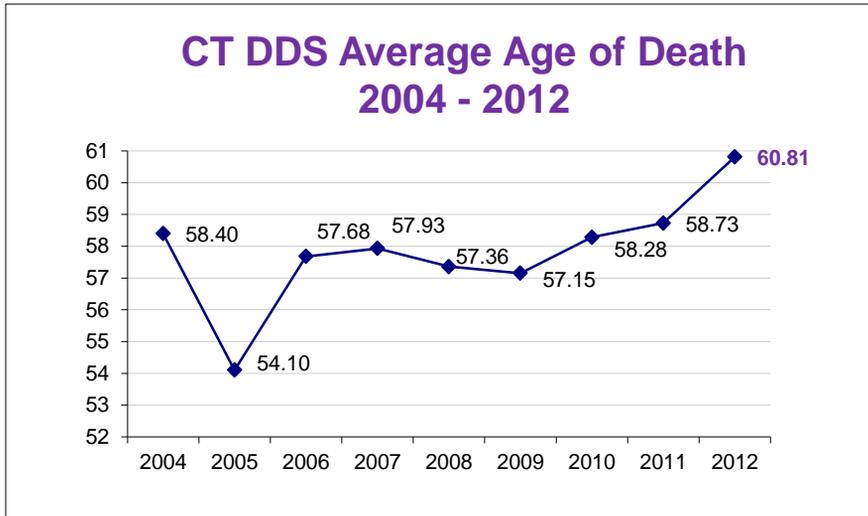
Figure 19 (above) illustrates mortality rate by age range. The data over the past five fiscal years reveals a consistent pattern of increasing mortality rates with each successive decade of life. The mortality rates increase markedly for adults who are in their fifth decade of life. The data also demonstrates that within each age range there is some fluctuation in mortality rates from one year to the next.

# Mortality ANNUAL Report - 2012

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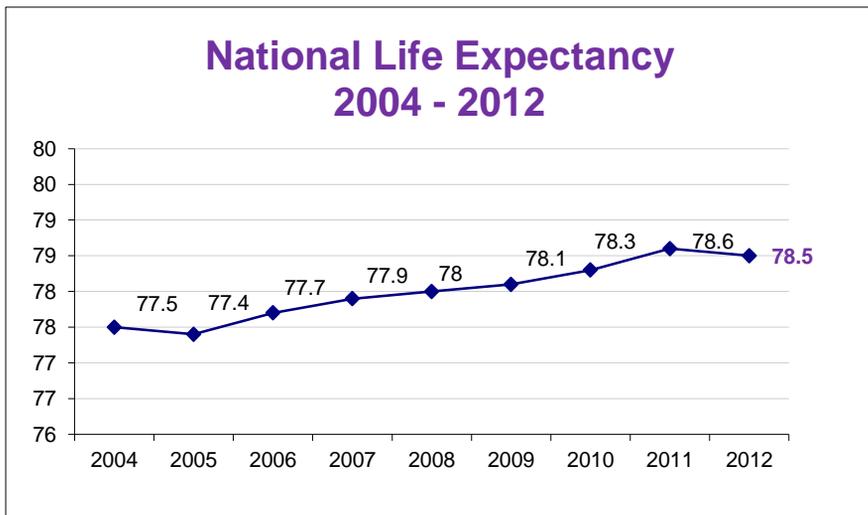
Section Four Continued

Figure 20



For the last eight fiscal years the average age of death has held in a tight range within the fifth decade of life. This is lower than the national life expectancy (78.6) and the Connecticut life expectancy (80.2).<sup>19, 27</sup>

Figure 21



# Mortality ANNUAL Report - 2012

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Section Four Continued

Table 7

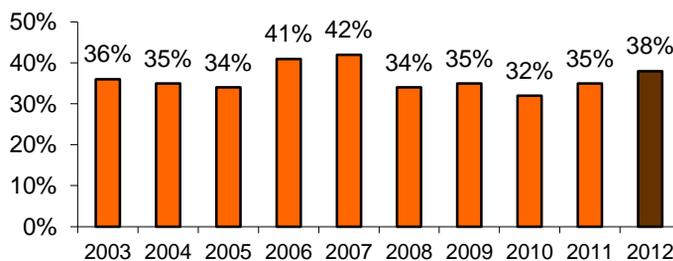
## RESIDENCE AT TIME OF DEATH TRENDS (2003 - 2012)

	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
SNF	30%	35%	40%	33%	33%	30%	31%	28%	31%	32%
CLA	27%	31%	23%	31%	29%	26%	28%	33%	29%	33%
Family	20%	15%	19%	18%	17%	20%	18%	18%	19%	12%
STS	9%	7%	7%	10%	10%	13%	8%	14%	11%	11%
IHS/CRS	6%	3%	4%	4%	7%	5%	6%	2%	5%	6%
RC	5%	4%	4%	2%	2%	2%	5%	2%	1%	1%
CCH	1%	2%	1%	1%	1%	2%	2%	2%	3%	3%
Other	2%	0%	2%	0%	1%	2%	2%	1%	1%	2%
	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%

Table 7 depicts the percentage of deaths within various support types over a ten year period of time. Although there is some variability, the percentage of DDS deaths that occur in SNF's and CLA's is greater than other settings.

Figure 22

## Percent of Hospice Supports (2003 - 2012)



End of life planning and hospice care has been a hallmark of the CT DDS system as noted above. Where appropriate, end of life planning and support services were provided prior to death with the individual's team involved in the planning process. The continued integration of hospice supports into the person's support plan can be attributed to mortality review findings and recommendations. Case managers, nurses and other team members actively seek out hospice services in cases where death is anticipated as a result of a terminal illness.

# Mortality ANNUAL Report - 2012

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Section Four Continued

Table 8

**Location Where Death Pronounced  
(FY 2003 - 2012)**

Location	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	10 Year Total
Hospital	34	35	64	58	63	71	71	61	49	55	562
SNF	22	26	35	30	28	26	14	18	21	33	253
CLA	16	18	16	17	15	7	10	12	15	21	147
Hospital ER	9	4	18	14	16	9	13	12	9	10	114
STS	1	5	4	14	6	11	10	13	13	13	90
RC	11	5	3	2	1	0	1	1	1	0	25
IHS	4	3	4	5	3	3	5	3	3	5	38
Hospice	1	3	7	2	2	1	5	0	5	7	33
Other	1	0	1	3	3	5	4	1	1	2	21

Table 9

**Number of Autopsies (FY 2004 – FY 2011)**

FY 05	20	13%
FY 06	17	12%
FY 07	11	8%
FY 08	17	13%
FY 09	14	11%
FY 10	14	10%
FY 11	6	5%
FY 12	13	9%

As noted in Table 9 above the number of autopsies performed vary from one review year to the next. This variation can be attributed to the number of deaths in a given year, the specific death related circumstances and requests for consent post mortems by family members. The number of post mortem examinations during FY 2012 increased from FY 2011 (5% vs. 9%).

# Mortality ANNUAL Report - 2012

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## SECTION FIVE: LEADING CAUSES OF DEATH

This section discusses cause of death data for people served by the CT DDS. The information used to determine the cause of death for each individual was gathered from the DDS Death Report Form and/or the Certificate of Death.\* In addition the documented cause of death is also reviewed by the regional mortality committee and/or IMRB during the mortality review process.

Table 10

### Leading Cause of Death Data CT DDS (based on the 2012 fiscal year)



<b>21.8%</b>	<i>of deaths were due to</i>	<b>Heart Disease</b>	<i>including</i>	Acute MI, CHF, Dysrhythmias, Pulmonary HTN, Asystole, Cardiomyopathy
<b>17.1%</b>	<i>of deaths were due to</i>	<b>Aspiration Pneumonia</b>	<i>including</i>	Aspiration Pneumonia
<b>14.2%</b>	<i>of deaths were due to</i>	<b>Respiratory Disease</b>	<i>including</i>	Respiratory Failure, Pulmonary Embolism, Influenza, Multi-System Failure, COPD, ARDS, Asthma
<b>13.3%</b>	<i>of deaths were due to</i>	<b>Cancer</b>	<i>including</i>	Wide variety of primary origin sites
<b>8.5%</b>	<i>of deaths were due to</i>	<b>Pneumonia</b>	<i>including</i>	Pneumonia
<b>3.3%</b>	<i>of deaths were due to</i>	<b>Sepsis</b>	<i>including</i>	Septicemia, Bacterial, Shock, Urosepsis, Peritonitis
<b>3.3%</b>	<i>of deaths were due to</i>	<b>Renal/Kidney</b>	<i>including</i>	Renal Failure chronic and acute
<b>1.9%</b>	<i>of deaths were due to</i>	<b>Alzheimer's Disease</b>	<i>including</i>	Dementia
<b>1.9%</b>	<i>of deaths were due to</i>	<b>Accident/Trauma</b>	<i>including</i>	Unintentional Injuries, Falls, Asphyxia, Choking, Trauma
<b>1.4%</b>	<i>of deaths were due to</i>	<b>Digestive System</b>	<i>including</i>	Intestinal Obstruction, Volvulus

The 10 leading causes of death in 2012 (Table 10) are noted above. Heart disease remains the leading cause of death for the DDS population with aspiration pneumonia, respiratory disease, cancer and pneumonia rounding out the top five.

## Heart Disease

Heart disease/cardiovascular disease remains the leading cause of death for the CT DDS population (21.8%). Cardiovascular disease is an umbrella term to describe any abnormal condition characterized by the dysfunction of the heart or blood vessels. Examples of diseases that fall within this category are congestive heart failure, cardiac arrhythmia, arteriosclerosis, ischemic heart disease, coronary artery disease, heart valve disease, hypertension, endocarditis, myocardial infarction, myocarditis, disease of the aorta, peripheral vascular disease and others.

\* CT DDS receives certificates of death and death reports for all deaths reviewed.

# Mortality ANNUAL Report - 2012

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Section Five Continued

Table 11 provides an in-depth analysis of the cardiac deaths that were reviewed as part of the DDS mortality review process.\* In FY 12 more men died as a result of heart disease than women and women lived longer than men.

Table 11

## Deaths Due to Heart Disease

Year	Number of	Number of	Average Age	Average Age	Average Age
	Male Deaths	Female Deaths	Male	Female	
FY 10	23	24	62	62.7	62.4
FY 11	22	16	61.9	63	62.3
<b>FY 12</b>	<b>27</b>	<b>19</b>	<b>63.4</b>	<b>66.5</b>	<b>64.7</b>

As in the general population, many of the individuals served by DDS who died as a result of cardiovascular disease had at least one or more identified risk factors prior to their death such as high blood cholesterol, high blood pressure, coronary artery disease, peripheral vascular disease, congenital heart defects, congestive heart failure, physical inactivity, obesity and diabetes mellitus.

In the general population 80% of people who die of coronary heart disease are 65 or older <sup>25</sup> as compared with only 43% of individuals in the CT DDS population. Of the remaining cardiac related deaths in the DDS population group: Eighteen percent (18%) of the cardiac deaths occurred prior to the age of 50 years and 41% percent of the cardiac deaths occurred between the ages of 50-65.

There is a greater prevalence of congenital heart conditions and atrioventricular septal defects found in people with Down syndrome.<sup>20</sup> However, CT DDS data reveals that the incidence of cardiac deaths reported for people with Down syndrome was in line with the rest of the DDS population.

## Respiratory Disease

The 2012 leading cause of death data demonstrates the significant impact of respiratory disease in the CT DDS population.

An analysis of the cases reviewed by the CT DDS mortality review process revealed that more men died as a result of respiratory disease/aspiration pneumonia/pneumonia than women and that they died at a younger age.\*

Table 12

## Deaths Due to Respiratory Disease, Pneumonia and Aspiration Pneumonia

Year	Number of	Number of	Avg. Age of	Avg. Age of	Ave. Age
	Males	Females	Males	Females	
FY 10	26	13	61	64	62
FY 11	15	15	65.2	75.2	70.2
<b>FY 12</b>	<b>14</b>	<b>11</b>	<b>63.9</b>	<b>65.2</b>	<b>64.5</b>

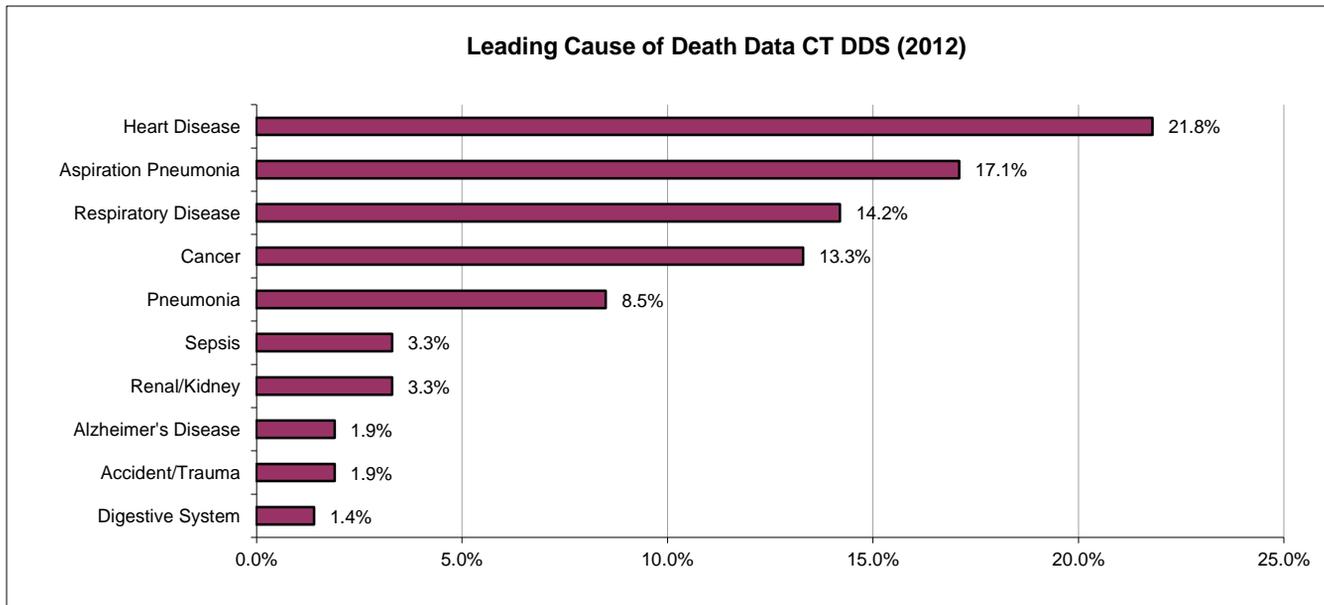
\* Does not include Abridged Reviews

# Mortality ANNUAL Report - 2012

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Section Five Continued

Figure 23



All diseases of the lung/respiratory system due to an identified respiratory disease process such as acute bronchitis, emphysema, asthma, pulmonary embolism, respiratory failure, COPD, ARDS, pneumonia and aspiration pneumonia were responsible for 39.8% of all deaths in 2012 eclipsing the number of deaths caused by cardiac disease (21.8%).

The frequency of respiratory disease (specifically pneumonia and aspiration pneumonia) and the resultant high mortality rate seem to be closely related to the risk factors of immobility and dysphagia or swallowing dysfunction, restrictive pulmonary function due to curvature of the spine, cerebral palsy, genetic syndromes, hiatal hernia and other anatomical anomalies which are prevalent in the population served by DDS.

## Alzheimer's Disease

Alzheimer's disease is tied for the eighth leading cause of death (1.9%) in the CT DDS leading cause of death statistics. During the mortality review process it was determined that in 22% of the 106 deaths, the person had a diagnosis of Alzheimer's disease at the time of their death.

# Mortality ANNUAL Report - 2012

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Section Five Continued

Table 13

## Leading Causes of Death CT DDS

Rank	CT DDS 2012	CT DDS 2011	CT DDS 2010	CT DDS 2009	CT DDS 2008	CT DDS 2007	CT DDS 2006
1	<b>Heart Disease</b> 21.8%	Heart Disease 22.5%	Heart Disease 28%	Heart Disease 29.9%	Heart Disease 31%	Heart Disease 29.1%	Heart Disease 25.4%
2	<b>Aspiration Pneumonia</b> 17.1%	Cancer 13.5%	Respiratory Disease 14.6%	Respiratory Disease 13.7%	Aspiration Pneumonia 15%	Respiratory Disease 18%	Respiratory Disease 18.2%
3	<b>Respiratory Disease</b> 14.2%	Aspiration Pneumonia 8.2%	Sepsis 12.9%	Pneumonia 12.8%	Respiratory Disease 12.3%	Cancer 11%	Pneumonia 14.4%
4	<b>Cancer</b> 13.3%	Respiratory Disease 11.1%	Cancer 12.9%	Aspiration Pneumonia 10.3%	Cancer 10.7%	Pneumonia 8.5%	Cancer 11%
5	<b>Pneumonia</b> 8.5%	Pneumonia 8.2%	Aspiration Pneumonia 12.3%	Sepsis 9.8%	Pneumonia 8.6%	Aspiration Pneumonia 8.5	Sepsis 7.8%
6	<b>Sepsis</b> 3.3%	Sepsis 5.3%	Pneumonia 7.6%	Cancer 7.4%	Sepsis 8.6%	Sepsis 6%	Aspiration Pneumonia 5.5%
7	<b>Kidney/ Renal</b> 3.3%	Alzheimer's Disease 4.4%	Stroke 4%	Stroke 3.4%	Nervous System 3.7%	Stroke 3.5%	Kidney/ Renal 4.4%
8	<b>Alzheimer's Disease</b> 1.9%	Digestive System 3.4%	Digestive System 3%	Kidney/ Renal 2.5%	Kidney/ Renal 3.2%	Kidney Renal 3.5%	Accident 2.7%
9	<b>Accident</b> 1.9%	Kidney/ Renal 3.4%	Kidney/ Renal 2%	Digestive System 2.5%	Stroke 2.7%	Digestive System 3%	Stroke 2.2%
10	<b>Digestive System</b> 1.4%	Stroke 2.4%	Genetic Disorder 2%	Genetic Disorder 2.5%	Digestive System 1.6%	Nervous System 2%	Nervous System 2.2%

### Based on 2012 Fiscal Year Data

Table 13 compares the top ten leading causes of death with CT DDS data from previous years.\* Heart disease remained as the leading cause of death in the CT DDS population. Also pneumonia and sepsis remained as the fifth and sixth cause of death. There were some changes in the cause of death rankings compared to the 2011 data. For example: Aspiration pneumonia and respiratory disease passed cancer to become the second and third leading cause of death. Kidney/renal disease was tied with sepsis as the sixth and seventh leading cause of death. Alzheimer's disease dropped to the eighth leading cause of death and digestive system dropped to the tenth leading cause of death. Unlike other recent years, this year accidents ranked within the top ten causes of death at ninth. Respiratory disease, aspiration pneumonia and pneumonia as a cause of death once again represented over 1/3 of all CT DDS deaths.

\* 2012 data is based on fiscal year data – the previous years' data was based on calendar year data.

# Mortality ANNUAL Report - 2012

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Section Five Continued

## Leading Causes of Death for People with Down Syndrome

Table 14

FY12

### Primary Cause of Death/Down Syndrome

Cardiac Arrest	10
Respiratory Failure	5
Aspiration Pneumonia	3
Alzheimer's Disease	1
Seizure Disorder	1
Sepsis	1
<b>Total</b>	<b>21</b>

This year cardiac arrest was the leading cause of death for persons with Down syndrome (48%). (Table 14)

Since 2006 aspiration pneumonia and respiratory failure have accounted for 54% of all deaths for people with Down syndrome. (Table 15)

DDS mortality findings are also in line with other research studies that indicate that the life expectancy among adults with Down syndrome is about 55 years of age.<sup>5,6,7,8</sup> The average age of death for people with Down syndrome in the CT DDS system is 55.5.

Based on the DDS Down syndrome and death data (Table 16) there is no appreciable difference in lifespan for those individuals with or without Alzheimer's disease.

Although Alzheimer's disease was rarely documented as a cause of death the majority of people with Down syndrome had a diagnosis of Alzheimer's disease at the time of their death (76%). This data supports other research studies that found increased prevalence of Alzheimer's disease in people with Down syndrome.<sup>4,5</sup>

Table 15

FY 06 - FY 12

### Primary Cause of Death/Down Syndrome

Respiratory Failure	54
Cardiac Arrest	43
Aspiration Pneumonia	28
Renal Failure	4
Sepsis	4
Cancer	2
Gastrointestinal hemorrhage	2
Liver Disease	2
Pneumonia	2
Subdural hematoma	2
Alzheimer's disease	1
Anoxic brain damage	1
Asphyxia	1
CVA	1
Failure to thrive	1
Intracranial hemorrhage	1
Lymphoma	1
Seizure Disorder	1
<b>Total</b>	<b>151</b>

Table 16

### Average Age of Death Data

	2011	2012
Down syndrome:	55.6	55.5
Down syndrome and Alzheimer's disease:	58	56.1
Down syndrome without Alzheimer's disease:	52.9	54.9

# Mortality ANNUAL Report - 2012

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Section Five Continued

## Analysis of Cancer Deaths

Table 17

FY 12  
Analysis of Cancer Deaths

Primary Site	Number of Deaths	Average Age at Death
Pancreas	5	61.1
Breast	3	76.4
Colon	3	76.2
Lung	3	67.9
Leukemia	2	39.9
Renal	2	49.1
Stomach	2	56.2
Bladder	1	66.9
Brain	1	71.4
Bone	1	80.2
Cholangio	1	50.4
Liver	1	57.1
Lymphoma non Hodgkins	1	62.1
Myeloma	1	83.7
Prostate	1	90.6
<b>TOTAL</b>	<b>28</b>	<b>65</b>

### In FY 2012 cancer was the third leading cause of death for people supported by the CT DDS

For FY 12 the distribution of cancers in men were: Colorectal (2), leukemia (2), pancreas (2), stomach (2), bone (1), breast (1), cholangio (1), liver (1), lung (1), myeloma (1), prostate (1).

The FY 12 distribution of cancers in women were: Pancreas (3), breast (2), lung (2), renal (2), bladder (1), brain (1), colorectal (1), non-Hodgkins lymphoma (1).

The average age of death for all cancer victims (65 years) was above the average age of death for all CT DDS deaths (60.8 years).

The rate of death due to cancer in the CT DDS population (1.8/1000) is lower than the rate in the state of CT and nationally.<sup>25,26</sup>

Over the past 6 years cancers have represented 11% of CT DDS mortalities.

Table 18

FY 06 - FY12  
Analysis of Cancer Deaths

Primary Site	Number of Deaths	Average Age at Death
Lung	24	65.1
Pancreas	15	61.2
Breast	13	72.7
Colorectal	9	71.1
Stomach	8	58.8
Brain	7	62.7
Renal	7	54.6
Bladder	6	65.3
Leukemia	5	34.7
Liver	5	55.5
Lymphoma non-Hodgkins	5	59.9
Prostate	5	79.7
Esophagus	4	54.5
Myeloma	3	72.5
Cholagio	2	68.2
Gallbladder	2	57.2
Larynx	2	51.5
Lymphoma	2	65
Ovary	2	45.5
Parotid Gland	2	54.2
Thyroid	2	64.5
Adeno Carcinoma	1	46
Angiosarcoma	1	53
Aplastic Anemia	1	23
Bone	1	80.2
Endocrine/Adrenal Gland	1	61
Ethmoid Sinus	1	48
Lymphatic/Hemotopoietic	1	73
Nasopharyngeal	1	63.2
Neck	1	69.9
Oral/pharynx	1	68
Testicular	1	63
Trachael/Bronchus	1	81
Vulva	1	61.8
Unknown	4	61.9
<b>TOTAL</b>	<b>147</b>	<b>60.8</b>

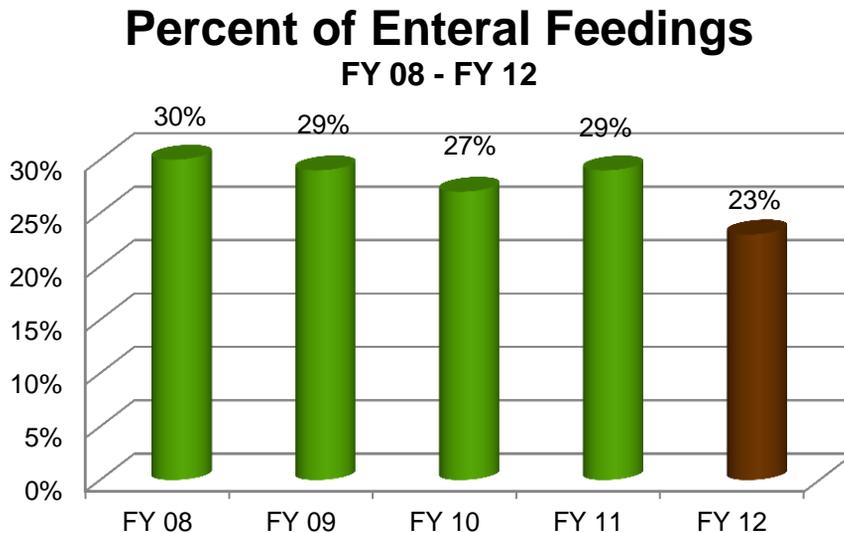
# Mortality ANNUAL Report - 2012

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Section Five Continued

## Enteral Feedings

Figure 24



The data reveals that during the past seven years 213 individuals were tube fed prior to their death. One hundred fifty-eight individuals had a gastrostomy tube, 28 had a jejunostomy tube and 27 had a gastrostomy and jejunostomy tube. In most cases the enteral feedings were initiated for one or more of the following reasons: Recurrent aspiration pneumonia, malnutrition and/or dementia. In fact, in FY2012 67% of these individuals had a history of recurrent pneumonia or aspiration pneumonia or dementia before insertion of the feeding tube.

The immediate cause of death in the majority of these cases was attributed to pneumonia, aspiration pneumonia or respiratory failure. And within the CT DDS mortality population there did seem to be an increase in the incidence of pneumonia/aspiration pneumonia or risk of mortality associated with enteral tube feeding. Therefore, the DDS data seemed to validate other studies which suggest that people who require enteral feeding tubes have a higher rate of pneumonia and pneumonia related death.<sup>11,12,13,16,17,21</sup>

The gender and/or level of intellectual disability of CT DDS individuals who were tube fed did not have an impact on mortality. However, an individual's unique clinical profile did seem to be an important factor in predicting risk of mortality post artificial enteral nutrition.

- This preliminary analysis of the CT DDS mortality data suggests that the risk associated with tube feeding may outweigh the benefits. In this regard the CT DDS data is consistent with other studies that failed to show that intervention by tube feeding is an effective treatment approach in supporting people who are on a dying trajectory due to a chronic illness.<sup>14,15,16,18,22,23,24</sup> However, the lack of evidence based research to support the practice of feeding tube placement (G/J) in the ID/DD population suggests that further investigation would be of considerable importance to practitioners in this field.

\* Based on data from all 106 cases reviewed by the CT mortality review process – does not include abridged reviews.

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## SECTION SIX: BENCHMARKS

### Mortality Rate Comparison

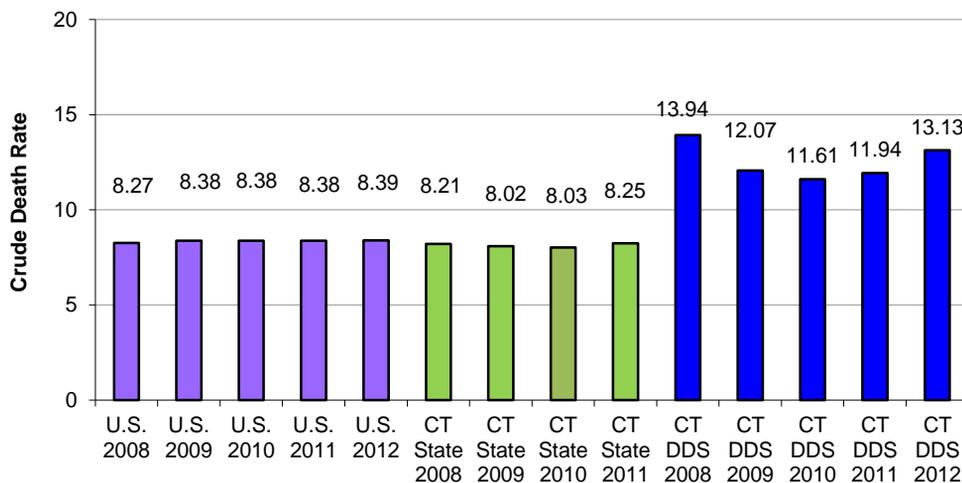
Benchmarks are standards by which similar items can be compared and allow the reader to place findings in context. Thus, the use of benchmarks including comparative data from other populations is an important mechanism for helping to understand analytical findings and trend data such as those presented in this report.

As mentioned in previous DDS Mortality Reports there are few relative benchmarks (data from other state agencies) available for use in comparing mortality data for persons with ID/DD and when data does exist, there may be differences in the way the data is reported and analyzed.

The overall CT DDS crude death rate of 13.13/1000 is higher than the rate of 8.25 in Connecticut (2011) and the rate of 8.39 in the general United States population (2012).<sup>1,25</sup> This would be expected due to the many health and functional complications associated with intellectual disabilities.

Figure 25

Overall Death Rate  
Comparison of Average Death Rates/1,000



While comparison of CT DDS mortality data with benchmarks from the general population (state and national) are of interest they are not very practical for direct comparison purposes due to differences in population characteristics, adjusted age and statistical methods etc.<sup>1,25,26</sup>

In this report we use the term “average death rate” to reflect what is more commonly referred to as the “crude” death rate in mortality and epidemiological research. It is a measure of how many people out of every thousand served by CT DDS died within the fiscal year. It is determined by multiplying the number of individuals who died during the year times one thousand and dividing this number by the total number of individuals served by DDS during the same period of time.

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Section Six Continued

Table 19

## Comparison Leading Causes of Death National, State of CT and CT DDS (based on calendar year)

Rank	US 2011	US 2010	US 2009	STATE CT 2009	CT DDS 2012	CT DDS 2011	CT DDS 2010	CT DDS 2009
1	Heart Disease 23.7%	Heart Disease 24.1%	Heart Disease 25.6%	Heart Disease 24.6%	Heart Disease 28.2%	Heart Disease 27.4%	Heart Disease 28%	Heart Disease 29.9%
2	Cancer 22.9%	Cancer 23.3%	Cancer 23.3%	Cancer 23.7%	Respiratory Disease 18.1%	Cancer 13.5%	Respiratory Disease 14.6%	Respiratory Disease 13.7%
3	Respiratory Disease 5.7%	Respiratory Disease 5.6%	Respiratory Disease 5.6%	Stroke 5.1%	Aspiration Pneumonia 12.5%	Aspiration Pneumonia 8.2%	Sepsis 12.9%	Pneumonia 12.8%
4	Stroke 5.1%	Stroke 5.2%	Stroke 5.3%	Respiratory Disease 5%	Cancer 10.7%	Respiratory Disease 11.1%	Cancer 12.9%	Aspiration Pneumonia 10.3%
5	Accidents 4.9%	Accidents 4.8%	Accidents 4.8%	Accidents 4.1%	Sepsis 5.6%	Pneumonia 8.2%	Aspiration Pneumonia 12.3%	Septicemia 9.8%
6	Alzheimer's Disease 3.4%	Alzheimer's Disease 3.4%	Alzheimer's Disease 3.2%	X	Pneumonia 4.6%	Sepsis 5.3%	Pneumonia 7.6%	Cancer 7.4%
7	Diabetes 2.9%	Diabetes 2.8%	Diabetes 2.8%	X	Accidents 1.9%	Alzheimer's Disease 4.4%	Stroke 4%	Stroke 3.4%
8	Influenza/ Pneumonia 2.1%	Nephritis/ Kidney 2%	Influenza/ Pneumonia 2.2%	X	Digestive System 1.4%	Kidney/ Renal 3.4%	Digestive System 3%	Kidney/ Renal 2.5%
9	Nephritis/ Kidney 1.8%	Influenza/ Pneumonia 1.5%	Nephritis/ Kidney 2%	X	Kidney/ Renal 1.4%	Digestive System 3.4%	Kidney/ Renal 2%	Digestive System 2.5%
10	Intentional Self-Harm 1.5%	Intentional Self-Harm 1.5%	Intentional Self-Harm 1.5%	X	Stroke 1.4%	Stroke 2.4%	Genetic Disorder 2%	Genetic Disorder 2.5%

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Section Six Continued

## Leading Causes of Death Benchmarks: National, State of CT and CT DDS

Table 19 compares the top ten leading causes of death for people served by CT DDS with vital statistics benchmarks data for the State of Connecticut, and United States. Year over year data comparisons continue to demonstrate consistency in the leading causes of death data.<sup>1,25,26</sup>

**Heart Disease:** (Due to various cardiac diagnoses) is the number one cause of death for all of the referenced populations. As in past years the prevalence of cardiac disease is slightly greater in the DDS population at 28.2% versus 23.7% in the CT general population and 24.1% nationally.

**Respiratory Diseases:** Is the second leading cause of death in the CT DDS population (18.1%). This category which includes influenza causes death in the CT DDS population at a rate 3 times the rates reported in the CT and national vital statistics data base (5%) and (5.7%) respectively .

**Aspiration Pneumonia:** Is the third leading cause of death in the DDS population (12.5%) and as mentioned earlier in this report is unique to the ID/DD population due to many factors including the prevalence of dysphagia, Down syndrome, Alzheimer's disease and enteral feedings. In comparison, aspiration pneumonia is not reflected in the state of CT or national vital statistics as one of the top ten leading causes of death.

**Cancer:** Is the fourth leading cause of death in the CT DDS population responsible for 10.7% of deaths. Unlike the other mentioned leading causes of death, cancer in DDS occurs less frequently in the CT DDS population than in the CT (23.7%) and national (22.9) general populations.

**Septicemia:** Originating from various sites and usually acute in onset is the fifth leading cause of death in the CT DDS population resulting in 5.6% of deaths while only 1.4% of deaths in the US general population are caused by sepsis.

**Pneumonia:** Is the sixth leading cause of death accounting for 4.6% of CT DDS deaths compared to <3% in the US population. Many of the multiple co-morbidities found in the CT DDS ID/DD population such as cerebral palsy, congenital syndromes, epilepsy, GERD, hiatal hernia, and immuno-deficiency disorders result in a compromised pulmonary system that makes this population vulnerable for developing pneumonia.

**Accidental Deaths:** In calendar year 2012 the percent of deaths resulting from accidents in the CT DDS system (1.9%) was the seventh leading causes of death and once again was lower than the number of accidental deaths reported in the 2009 CT population (4.1%) and 2011 US population (4.9%).

**Caution:** While comparison of CT DDS mortality data with benchmarks from the general population (state and national) are of interest, they are not very practical for direct comparison purposes due to differences in population characteristics, adjusted age and statistical methods etc. For example, the special health concerns (co-morbidities) inherent in people with intellectual disabilities are related to a greater mortality rate. Also, many individuals in the CT DDS system had a diagnosis of dysphagia and or gastroesophageal reflux disease at the time of their death. Both of which have been linked to aspiration pneumonia, respiratory failure, sepsis and death in the ID/DD population.<sup>2,9</sup>

**Seasonal variations in mortality require consistency when conducting comparative analysis and, therefore, the previous data regarding leading causes of death is based on the calendar year 2012. Leading cause of death data for the calendar year will allow benchmark data from CT DDS to be consistent with Connecticut and national mortality benchmarks developed for the general population calendar year.**

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## SECTION SEVEN: SUMMARY MORTALITY CASE REVIEW FINDINGS

The CT DDS mortality review process has evolved into a powerful quality assurance system for ensuring the delivery of optimal health care oversight and services in the CT DDS. The regional and state recommendations regarding health care oversight and standardization of health care practices for professional and non-professional staff have improved basic health care services and mitigated health related risk. The impact of mortality findings and recommendations has been observed within DDS and has extended to community based health care providers including practitioners in private practice licensed nursing facilities, acute care hospitals, hospice providers, health and dental clinics and other state agencies.

Table 20

### Mortality Case Review Summary (FY 2011)

<i>Death Reviewed By Regional Committees</i>	<i>Cases Closed at Regional Level</i>	<i>Cases Referred and Reviewed By IMRB</i>	<i>QA Cases Closed by Region IMRB Review</i>	<i>Total Cases Reviewed By IMRB</i>
147	110 (75%)	37 ( 25%)	10 (7%)	47 (32%)

Table 20 above provides a summary of all deaths reviewed by the CT DDS Mortality Review Committees. Seventy-five percent of the 147 cases reviewed were closed by the local regional mortality committees. The regional committees referred 37 mortality cases to the state Independent Mortality Review Board for further review. The reasons for the case referrals are noted in Table 21 (below).

The CT DDS Mortality Review Process requires that at least 10% of all cases that are closed at the regional level are reviewed by the Independent Mortality Review Board (IMRB) for quality assurance purposes. This year the IMRB reviewed 15% of cases closed by regional mortality committees.

Table 21

<b>Cases Referred to IMRB (37)</b>	
Medical/Health Care	14
Post Mortem Examination	13
Pending Abuse/Neglect Investigations	10

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Section Seven Continued

## CT DDS Mortality Review: General Findings

### Predictors of Mortality in the ID Population

- age
- mobility status
- the need for special assistance when eating
- sudden or progressive weight loss
- level of intellectual disability
- a distinct cluster of co-morbidities
- chronic aspiration pneumonia
- pneumonias that result in hospitalization

## I. Findings and Quality Enhancement Action

Mortality Review Finding	DDS Quality Enhancement Action
Health care coordination by registered nurses is an essential support for the ID/DD population who are at risk for chronic and acute health conditions.	<ul style="list-style-type: none"> <li>• <b>Timely nursing assessments</b> consistently result in appropriate referral and treatment by medical practitioners.</li> <li>• The department has enhanced the <b>Care Coordination Tool</b> to assist nurses to effectively establish and monitor the various providers servicing clients and the specific care to be provided.</li> </ul>
The premature onset of acute and chronic health issues which lead to morbidity and mortality in people with ID presents a unique challenge to caregivers.	<ul style="list-style-type: none"> <li>• This year we will update our <b>Routine Preventive Health Care Guidelines for Persons with Intellectual/Developmental Disabilities</b> based on the U.S. Preventive Services Task Force (USPSTF) recommendations on screening, counseling, and preventive medication topics and includes clinical considerations for each topic.</li> </ul>
The CT DDS process for reviewing advanced life directives including the withholding of cardiopulmonary resuscitation (DNRs) provides the team with a foundation for quality end of life planning.	<ul style="list-style-type: none"> <li>• Connecticut DDS will continue its <b>stringent protocol</b> for the monitoring of all contemplated or existing <b>Do Not Resuscitate (DNR)</b> orders for all adjudicated individuals treated under the direction of the Commissioner of the Department of Developmental Services (DDS).</li> </ul>
End of life planning that included hospice services and supports allowed many individuals with irreversible or terminal conditions to remain in their home or current residence.	<ul style="list-style-type: none"> <li>• Reinforced commitment to ensuring individuals remain in their homes and communities regardless of their ability or age.</li> <li>• Individuals are supported to <b>die with dignity where they have lived</b>. This policy and philosophical position applies to all individuals for whom the department bears direct or oversight responsibility for medical care.</li> </ul>
CT DDS mortality cases referred to the CT Department of Public Health resulted in improvements in healthcare facility and/or health care practitioners standards of practice which we expect will ultimately advance the quality of care for people with ID/DD.	<ul style="list-style-type: none"> <li>• DDS continues to <b>foster partnerships</b> with DPH, OPA and other health care systems and facilities. For example, our recent sharing of the dysphagia training curriculum with skilled nursing facilities to enhance education and awareness of how to provide oral hygiene to individuals with I/DDs.</li> </ul>
Fall risk has been identified as a consistent area of concern through our mortality review process	<ul style="list-style-type: none"> <li>• Developed and initiated a <b>Fall Prevention Protocol</b>, projected implementation July 2013. This protocol is designed to reduce the incidence of falls and injuries related to falls. Fall prevention protocols have been adopted and implemented by our provider agencies across the state.</li> </ul>

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Section Seven Continued

## II. General Community Awareness Findings

These are general findings that we believe the community at large should be aware of.

1. Individuals living in their own home or receiving individualized supports benefit from health education and training that focuses on health promotion and disease prevention.
2. Post mortem examinations are a valuable tool to confirm the cause and manner of death in cases where the cause of death was not immediately determined.
3. As individuals age within the ID/DD population it presents a future challenge for the CT DDS service system and for all care providers, but must be embraced through creative solutions and strengthened partnerships.
4. The aging Down syndrome population requires specialized and comprehensive supports.
5. CT DDS has sustained quality in the area of water temperature safety. There have been no mortality events related to scalding. The anti scalding devices continue to assist in ensuring maximum water temperature safety practices.

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**The next Annual Mortality Report UPDATE will be issued in March of 2014**

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**Report prepared by Dory McGrath, MN, RN and Lakisha Hyatt, MSN, RN.  
With thanks to Julie Bouchard with assistance from Tim Deschanes-Desmond.**

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## **APPENDICES**

**Appendix A: Overview of DDS Population**

**Appendix B: DDS Consumers by Residential Setting  
DDS Population by Age**

**Appendix C: Percentage Population by Age Ranges  
Level of Intellectual Disability**

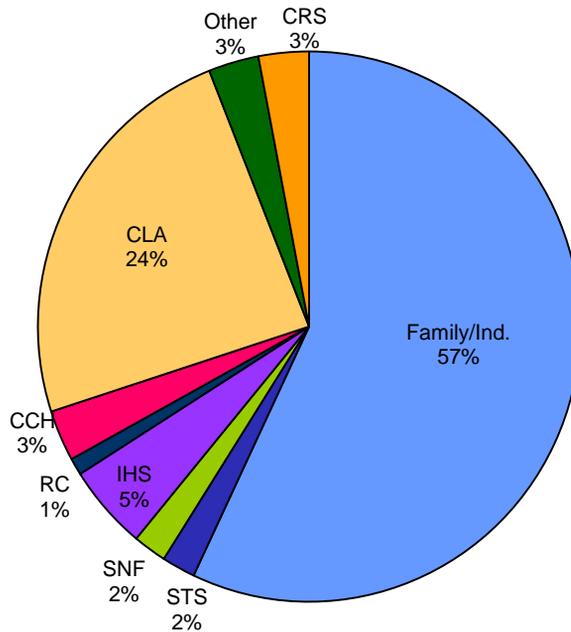
**Appendix D: Age Category and Residence  
Consumers by Program Type**

## APPENDIX A

### Overview of DDS Population

Intellectual Disability is a developmental disability that is present in about 1% of the Connecticut population. In order for a person to be eligible for DDS services they must have significant deficits in intellectual functioning and in adaptive behavior, both before the age of 18 yrs. As of June 30, 2012 **15,858** individuals with intellectual disability were being supported by the department.

#### Overview of DDS Population Percentage by Setting



Over half of the people served by CT DDS live at home with their family. Almost one third receive support services provided in community living arrangements (CLAs), community companion homes (CCH), regional centers (RC) and a campus program, Southbury Training School (STS). Approximately 8% of the DDS population receive individualized home supports (IHS) or continuous residential supports (CRS). The remainder (5%) of the people are supported by other state or local government and/or private entities including licensed nursing facilities (SNF), the CT Department of Mental Health and Addiction Services, the CT Department of Children and Families, the CT Department of Corrections and residential schools.

## APPENDIX B

### DDS CONSUMERS BY RESIDENTIAL SETTING

FY 2011 - FY 2012

Type of Support	2012	2012	2011	2011	2011-2012
	# of Consumers	Percent	# of Consumers	Percent	% Change
Family	7,861	50%	7,912	51%	(-0.6%)
CLA (Group Home)	3,757	24%	3,791	24%	(-0.9%)
IHS, CRS	2,419	15%	2,048	12%	18.1%
Training School	401	2%	429	3%	(-6.5%)
Other	463	3%	439	3%	5.5%
Community Companion Home (CCH)	401	3%	413	3%	(-2.9%)
SNF	345	2%	381	2%	(-9.4%)
Regional Center (RC)	211	1%	227	2%	(-7.0)
<b>TOTAL</b>	<b>15,858</b>	<b>100%</b>	<b>15,640</b>	<b>100%</b>	

### DDS Resident Population by Age

2007 - 2012

	2012	2011	2010	2009	2008	2007
Children (0-19)	3,281	3,322	3,456	3,576	3,594	3,575
Adults (20 - over)	12,577	12,318	12,039	11,814	11,676	11,573
<b>TOTAL ALL AGES</b>	<b>15,858</b>	<b>15,640</b>	<b>15,495</b>	<b>15,390</b>	<b>15,270</b>	<b>15,148</b>

<b>Adults (55 - over)</b>	<b>3,121</b>	<b>3,019</b>	<b>2,893</b>	<b>2,779</b>	<b>2,628</b>	<b>2,587</b>
<b>Adults (65 - over)</b>	<b>1,243</b>	<b>1,156</b>	<b>1,105</b>	<b>1,050</b>	<b>1,005</b>	<b>991</b>

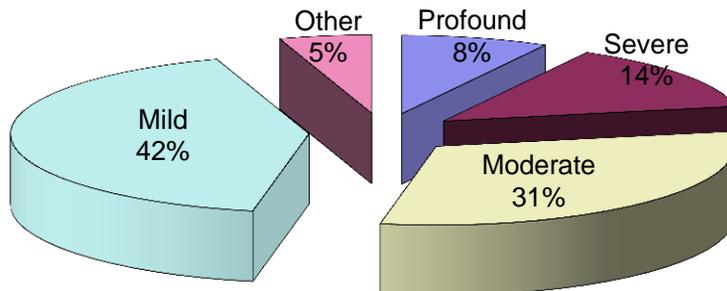
## APPENDIX C

### Percent Population by Age Ranges

FY 2012

AGE RANGE	TOTAL	% OF TOTAL
Age 0-19	3,281	20.7%
Age 20-29	3,546	22.4%
Age 30-39	2,218	14.0%
Age 40-49	2,394	15.1%
Age 50-59	2,357	14.9%
Age 60-69	1,367	8.6%
Age 70-79	508	3.2%
Age 80+	187	1.2%
<b>TOTAL</b>	<b>15,858</b>	<b>100%</b>

### CT DDS Population - Level of Intellectual Disability



## APPENDIX D

### AGE CATEGORY AND RESIDENCE

FY 2012

Residence Type	Children (0-19)	Adults (20-64)	Older Adults (65+)	TOTALS
CLA (Group Home)	82	3,191	484	3,757
CRS (Continuous Residential Supports)	2	420	28	450
CCH (Community Companion Home)	6	346	49	401
Family Home/Independent Living	2,587	5,049	225	7,861
IHS (Individualized Home Supports)	432	1,481	56	1,969
Regional Center	0	205	6	211
SNF (Skilled Nursing Facility)	0	158	187	345
STS (Southbury Training School)	0	243	158	401
Other	172	241	50	463
<b>TOTAL</b>	<b>3,281</b>	<b>11,334</b>	<b>1,243</b>	<b>15,858</b>
<b>PERCENT</b>	<b>21%</b>	<b>71%</b>	<b>8%</b>	<b>100%</b>

#### Consumers Age 19 - 64 Years By Program Type

CLA	85%
CRS	93%
CCH	86%
Family/Independent	64%
IHS	75%
RC	97%
SNF	46%
STS	61%

#### Consumers over the Age of 65 By Program Type

CLA	13%
CRS	6%
CTH	12%
Family/Independent	3%
IHS	3%
RC	3%
SNF	54%
STS	39%